<u>Attendees (alphabetical):</u> Dr. John Carpten—TGen; Dr. Louis Canfield—U of A; Carol—U of A; Sue Colvin—WRCCOP; Jeanette Dalrymple—Banner Health; Dr. Tim Flood—ADHS; Dr. Zeenat Mahal—PIMC; Chris Newton—ADHS; Amy Stoll—TGen; Veronica Vensor—ADHS

- I. Update on general CCC Meeting on May 10, 2006:
  - a. Tim Flood attend the meeting
  - b. He reported on the Network Analysis that the Research Committee adopted and has recommended to the CCC Committee
  - c. There is information on the details of this on pg 4 of the CCC Committee meeting minutes
  - d. Another CCC Committee meeting is coming up in 3-4 weeks
- II. ADHS Cancer Registry identified data from the central registry on tissue samples from cancer patients
  - a. Chris Newton, Veronica Vensor and Tim Flood from the ADHS AZ Cancer Registry presented the data to the research CCC committee—one spreadsheet and one document were distributed for review
  - b. This type of data identifies facilities where tissue is stored in AZ and help identifies where there is access to tissues
  - c. The this data can also help evaluate what is being collected among different ethnic groups and areas in the state
  - d. The layout of the excel spreadsheet named tissuebank0103.xls is as follows:
    - i. Five types of cancer are listed one per worksheet: colorectal, lung, breast, prostate, childhood leukemia (ages 0-14)
    - ii. Each worksheet has listed the ten most common facilities where the tissue is excised, and the number of tissues at these facilities by race/ethnicity.
    - iii. Also listed on the "README" sheet is the total number of cases for the selected sites combined, the number of cases with tissue removed for the selected sites combined, and the percent total for these cases
    - iv. The data includes cases for Native Americans from the non-federal hospitals, the HIS, and the VA, and the registry feels that they have complete ascertainment of the Native American cancer cases in AZ for this analysis
    - v. Tissue removal is categorized as definitive surgery in the registry data, and excisional biopsies are included
    - vi. For the leukemia cases—bone marrow biopsy is included
    - vii. Only 16% of lung cases have tissue removed so the numbers are small
  - e. The WRCCOP commented that there is tremendous difficulty in getting specimens especially when they want to be used for future research
  - f. Discussion on how to make it easier to obtain tissue specimens
    - i. Suggestion: Do an educational seminar (1/2 day or one day) for pathologists on the importance of collecting the tumor specimens

- and having them available to researchers; explain why the researchers need it
- ii. NSABP study looked at previously collected tumor specimens and the value of the medium for analysis—conclusion was that for genomic research it is imperative that the tissue is fresh or frozen, not paraffin-embedded—collection in RNA later is fine for cellular morphology, and some tissues frozen temporarily can be used
- iii. Tim Flood said he went to grand rounds at PCH and the pathologist in 1 hour described the high tech uses and genetic advances in pathology—very interesting
- iv. Louise Canfield—Tucson comment: is part of the difficulty in getting tissue a HIPAA issue? Answer: for older specimens in paraffin—yes, or if patient is deceased; for prospective collections maybe not as much of an issue
- v. When the patient goes to surgery—there was an inquiry about whether the option to share tissue was on the intake forms; those forms are starting to change in hospitals—need to look into that
- vi. All of these issues could be wrapped up into the same ½ day seminar/symposium
- vii. The symposium would be good for statewide pathologists
- g. What other tumor types would be valuable to know about how many current tissues have been collected?
  - i. Melanoma—in AZ, tricky because most biopsies are done in physicians' offices and therefore not kept.
  - ii. Pancreatic
  - iii. Gall bladder—small number of patients
  - iv. Biliary duct—include with liver cases
  - v. Stomach
- h. This analysis only identifies sites where the patient was diagnosed and the biopsy was taken
- i. Valuable to get a list of types of cancers common among certain populations in AZ—Native American (Pancreatic, kidney) and Hispanic (stomach, mult. Myeloma)
- j. Chris and Tim will run additional sites.

Next teleconference scheduled for Thursday, June 22, 2006. 12:00 pm.